

# Calendar No. 69

108TH CONGRESS  
1ST SESSION

# S. 538

To amend the Public Health Service Act to establish a program to assist family caregivers in accessing affordable and high-quality respite care, and for other purposes.

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## IN THE SENATE OF THE UNITED STATES

MARCH 5, 2003

Mrs. CLINTON (for herself, Mr. WARNER, Ms. MIKULSKI, Ms. SNOWE, Mr. BREAUX, Mr. JEFFORDS, Mrs. MURRAY, Ms. COLLINS, Mr. KENNEDY, Mr. SMITH, Mr. DODD, and Mr. NELSON of Nebraska) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

APRIL 10, 2003

Reported by Mr. GREGG, without amendment

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## A BILL

To amend the Public Health Service Act to establish a program to assist family caregivers in accessing affordable and high-quality respite care, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Lifespan Respite Care  
5 Act of 2003”.

1 **SEC. 2. LIFESPAN RESPITE CARE.**

2 The Public Health Service Act (42 U.S.C. 201 et  
3 seq.) is amended by adding at the end the following:

4 **“TITLE XXIX—LIFESPAN**  
5 **RESPITE CARE**

6 **“SEC. 2901. FINDINGS AND PURPOSES.**

7 “(a) FINDINGS.—Congress finds that—

8 “(1) an estimated 26,000,000 individuals in the  
9 United States care each year for 1 or more adult  
10 family members or friends who are chronically ill,  
11 disabled, or terminally ill;

12 “(2) an estimated 18,000,000 children in the  
13 United States have chronic physical, developmental,  
14 behavioral, or emotional conditions that demand  
15 caregiver monitoring, management, supervision, or  
16 treatment beyond that required of children generally;

17 “(3) nearly 4,000,000 individuals in the United  
18 States of all ages who have mental retardation or  
19 another developmental disability live with their fami-  
20 lies;

21 “(4) almost 25 percent of the Nation’s elders  
22 experience multiple chronic disabling conditions that  
23 make it necessary to rely on others for help in meet-  
24 ing their daily needs;

1           “(5) every year, approximately 600,000 Ameri-  
2           cans die at home and many of these individuals rely  
3           on extensive family caregiving before their death;

4           “(6) of all individuals in the United States  
5           needing assistance in daily living, 42 percent are  
6           under age 65;

7           “(7) there are insufficient resources to replace  
8           family caregivers with paid workers;

9           “(8) if services provided by family caregivers  
10          had to be replaced with paid services, it would cost  
11          approximately \$200,000,000,000 annually;

12          “(9) the family caregiver role is personally re-  
13          warding but can result in substantial emotional,  
14          physical, and financial hardship;

15          “(10) approximately 75 percent of family care-  
16          givers are women;

17          “(11) family caregivers often do not know  
18          where to find information about available respite  
19          care or how to access it;

20          “(12) available respite care programs are insuf-  
21          ficient to meet the need and are directed at pri-  
22          marily lower income populations and family care-  
23          givers of the elderly, leaving large numbers of family  
24          caregivers without adequate support; and

1           “(13) the limited number of available respite  
2       care programs find it difficult to recruit appro-  
3       priately trained respite workers.

4       “(b) PURPOSES.—The purposes of this title are—

5           “(1) to encourage States to establish State and  
6       local lifespan respite care programs;

7           “(2) to improve and coordinate the dissemina-  
8       tion of respite care information and resources to  
9       family caregivers;

10          “(3) to provide, supplement, or improve respite  
11       care services to family caregivers;

12          “(4) to promote innovative, flexible, and com-  
13       prehensive approaches to—

14           “(A) the delivery of respite care;

15           “(B) respite care worker and volunteer re-  
16       cruitment and training programs; and

17           “(C) training programs for family care-  
18       givers to assist such family caregivers in mak-  
19       ing informed decisions about respite care serv-  
20       ices;

21          “(5) to support evaluative research to identify  
22       effective respite care services that alleviate, reduce,  
23       or minimize any negative consequences of caregiving;  
24       and

1 “(6) to promote the dissemination of results,  
 2 findings, and information from programs and re-  
 3 search projects relating to respite care delivery, fam-  
 4 ily caregiver strain, respite care worker and volun-  
 5 teer recruitment and training, and training pro-  
 6 grams for family caregivers that assist such family  
 7 caregivers in making informed decisions about res-  
 8 pite care services.

9 **“SEC. 2902. DEFINITIONS.**

10 “In this title:

11 “(1) ELIGIBLE RECIPIENT.—The term ‘eligible  
 12 recipient’ means—

13 “(A) a State agency;

14 “(B) any other public entity that is capa-  
 15 ble of operating on a statewide basis;

16 “(C) a private, nonprofit organization that  
 17 is capable of operating on a statewide basis;

18 “(D) a political subdivision of a State that  
 19 has a population of not less than 3,000,000 in-  
 20 dividuals; or

21 “(E) any recognized State respite coordi-  
 22 nating agency that has—

23 “(i) a demonstrated ability to work  
 24 with other State and community-based  
 25 agencies;

1 “(ii) an understanding of respite care  
2 and family caregiver issues; and

3 “(iii) the capacity to ensure meaning-  
4 ful involvement of family members, family  
5 caregivers, and care recipients.

6 “(2) ADULT WITH A SPECIAL NEED.—The term  
7 ‘adult with a special need’ means a person 18 years  
8 of age or older who requires care or supervision to—

9 “(A) meet the person’s basic needs; or

10 “(B) prevent physical self-injury or injury  
11 to others.

12 “(3) CHILD WITH A SPECIAL NEED.—The term  
13 ‘child with a special need’ means a person less than  
14 18 years of age who requires care or supervision be-  
15 yond that required of children generally to—

16 “(A) meet the child’s basic needs; or

17 “(B) prevent physical self-injury or injury  
18 to others.

19 “(4) FAMILY CAREGIVER.—The term ‘family  
20 caregiver’ means an unpaid family member, a foster  
21 parent, or another unpaid adult, who provides in-  
22 home monitoring, management, supervision, or  
23 treatment of a child or adult with a special need.

24 “(5) RESPITE CARE.—The term ‘respite care’  
25 means planned or emergency care provided to a

1 child or adult with a special need in order to provide  
 2 temporary relief to the family caregiver of that child  
 3 or adult.

4 “(6) LIFESPAN RESPITE CARE.—The term ‘life-  
 5 span respite care’ means a coordinated system of ac-  
 6 cessible, community-based respite care services for  
 7 family caregivers of children or adults with special  
 8 needs.

9 **“SEC. 2903. LIFESPAN RESPITE CARE GRANTS AND COOP-**  
 10 **ERATIVE AGREEMENTS.**

11 “(a) PURPOSES.—The purposes of this section are—

12 “(1) to expand and enhance respite care serv-  
 13 ices to family caregivers;

14 “(2) to improve the statewide dissemination and  
 15 coordination of respite care; and

16 “(3) to provide, supplement, or improve access  
 17 and quality of respite care services to family care-  
 18 givers, thereby reducing family caregiver strain.

19 “(b) AUTHORIZATION.—Subject to subsection (f), the  
 20 Secretary is authorized to award grants or cooperative  
 21 agreements to eligible recipients who submit an applica-  
 22 tion pursuant to subsection (d).

23 “(c) FEDERAL LIFESPAN APPROACH.—In carrying  
 24 out this section, the Secretary shall work in cooperation  
 25 with the National Family Caregiver Support Program Of-

1 ficer of the Administration on Aging, and respite care pro-  
 2 gram officers in the Administration for Children and Fam-  
 3 ilies, the Administration on Developmental Disabilities,  
 4 the Maternal and Child Health Bureau of the Health Re-  
 5 sources and Services Administration, and the Substance  
 6 Abuse and Mental Health Services Administration, to en-  
 7 sure coordination of respite care services for family care-  
 8 givers of children and adults with special needs.

9 “(d) APPLICATION.—

10 “(1) SUBMISSION.—Each eligible recipient de-  
 11 siring to receive a grant or cooperative agreement  
 12 under this section shall submit an application to the  
 13 Secretary at such time, in such manner, and con-  
 14 taining such information as the Secretary shall re-  
 15 quire.

16 “(2) CONTENTS.—Each application submitted  
 17 under this section shall include—

18 “(A) a description of the applicant’s—

19 “(i) understanding of respite care and  
 20 family caregiver issues;

21 “(ii) capacity to ensure meaningful in-  
 22 volvement of family members, family care-  
 23 givers, and care recipients; and



1 “(iii) collaboration with other State  
 2 and community-based public, nonprofit, or  
 3 private agencies;

4 “(B) with respect to the population of fam-  
 5 ily caregivers to whom respite care information  
 6 or services will be provided or for whom respite  
 7 care workers and volunteers will be recruited  
 8 and trained, a description of—

9 “(i) the population of family care-  
 10 givers;

11 “(ii) the extent and nature of the res-  
 12 pite care needs of that population;

13 “(iii) existing respite care services for  
 14 that population, including numbers of fam-  
 15 ily caregivers being served and extent of  
 16 unmet need;

17 “(iv) existing methods or systems to  
 18 coordinate respite care information and  
 19 services to the population at the State and  
 20 local level and extent of unmet need;

21 “(v) how respite care information dis-  
 22 semination and coordination, respite care  
 23 services, respite care worker and volunteer  
 24 recruitment and training programs, or  
 25 training programs for family caregivers

1 that assist such family caregivers in mak-  
2 ing informed decisions about respite care  
3 services will be provided using grant or co-  
4 operative agreement funds;

5 “(vi) a plan for collaboration and co-  
6 ordination of the proposed respite care ac-  
7 tivities with other related services or pro-  
8 grams offered by public or private, non-  
9 profit entities, including area agencies on  
10 aging;

11 “(vii) how the population, including  
12 family caregivers, care recipients, and rel-  
13 evant public or private agencies, will par-  
14 ticipate in the planning and implementa-  
15 tion of the proposed respite care activities;

16 “(viii) how the proposed respite care  
17 activities will make use, to the maximum  
18 extent feasible, of other Federal, State,  
19 and local funds, programs, contributions,  
20 other forms of reimbursements, personnel,  
21 and facilities;

22 “(ix) respite care services available to  
23 family caregivers in the applicant’s State  
24 or locality, including unmet needs and how  
25 the applicant’s plan for use of funds will

1 improve the coordination and distribution  
2 of respite care services for family care-  
3 givers of children and adults with special  
4 needs;

5 “(x) the criteria used to identify fam-  
6 ily caregivers eligible for respite care serv-  
7 ices;

8 “(xi) how the quality and safety of  
9 any respite care services provided will be  
10 monitored, including methods to ensure  
11 that respite care workers and volunteers  
12 are appropriately screened and possess the  
13 necessary skills to care for the needs of the  
14 care recipient in the absence of the family  
15 caregiver; and

16 “(xii) the results expected from pro-  
17 posed respite care activities and the proce-  
18 dures to be used for evaluating those re-  
19 sults; and

20 “(C) assurances that, where appropriate,  
21 the applicant shall have a system for maintain-  
22 ing the confidentiality of care recipient and  
23 family caregiver records.

24 “(e) REVIEW OF APPLICATIONS.—

1           “(1) ESTABLISHMENT OF REVIEW PANEL.—

2           The Secretary shall establish a panel to review appli-  
3           cations submitted under this section.

4           “(2) MEETINGS.—The panel shall meet as often  
5           as may be necessary to facilitate the expeditious re-  
6           view of applications.

7           “(3) FUNCTION OF PANEL.—The panel shall—

8                   “(A) review and evaluate each application  
9                   submitted under this section; and

10                   “(B) make recommendations to the Sec-  
11           retary concerning whether the application  
12           should be approved.

13           “(f) AWARDING OF GRANTS OR COOPERATIVE  
14   AGREEMENTS.—

15           “(1) IN GENERAL.—The Secretary shall award  
16           grants or cooperative agreements from among the  
17           applications approved by the panel under subsection  
18           (e)(3).

19           “(2) PRIORITY.—When awarding grants or co-  
20           operative agreements under this subsection, the Sec-  
21           retary shall give priority to applicants that show the  
22           greatest likelihood of implementing or enhancing  
23           lifespan respite care statewide.

24           “(g) USE OF GRANT OR COOPERATIVE AGREEMENT  
25   FUNDS.—

1 “(1) IN GENERAL.—

2 “(A) MANDATORY USES OF FUNDS.—Each  
3 eligible recipient that is awarded a grant or co-  
4 operative agreement under this section shall use  
5 the funds for, unless such a program is in exist-  
6 ence—

7 “(i) the development of lifespan res-  
8 pite care at the State and local levels; and

9 “(ii) an evaluation of the effectiveness  
10 of such care.

11 “(B) DISCRETIONARY USES OF FUNDS.—  
12 Each eligible recipient that is awarded a grant  
13 or cooperative agreement under this section  
14 may use the funds for—

15 “(i) respite care services for family  
16 caregivers of children and adults with spe-  
17 cial needs;

18 “(ii) respite care worker and volunteer  
19 training programs; or

20 “(iii) training programs for family  
21 caregivers to assist such family caregivers  
22 in making informed decisions about respite  
23 care services.

24 “(C) EVALUATION.—If an eligible recipient  
25 uses funds awarded under this section for an

1 activity described in subparagraph (B), the eli-  
2 gible recipient shall use funds for an evaluation  
3 of the effectiveness of the activity.

4 “(2) SUBCONTRACTS.—Each eligible recipient  
5 that is awarded a grant or cooperative agreement  
6 under this section may use the funds to subcontract  
7 with a public or nonprofit agency to carry out the  
8 activities described in paragraph (1).

9 “(h) TERM OF GRANTS OR COOPERATIVE AGREE-  
10 MENTS.—

11 “(1) IN GENERAL.—The Secretary shall award  
12 grants or cooperative agreements under this section  
13 for terms that do not exceed 5 years.

14 “(2) RENEWAL.—The Secretary may renew a  
15 grant or cooperative agreement under this section at  
16 the end of the term of the grant or cooperative  
17 agreement determined under paragraph (1).

18 “(i) SUPPLEMENT, NOT SUPPLANT.—Funds made  
19 available under this section shall be used to supplement  
20 and not supplant other Federal, State, and local funds  
21 available for respite care services.

22 “(j) AUTHORIZATION OF APPROPRIATIONS.—There  
23 are authorized to be appropriated to carry out this sec-  
24 tion—

25 “(1) \$90,500,000 for fiscal year 2004; and

1           “(2) such sums as are necessary for fiscal years  
2           2005 through 2008.

3   **“SEC. 2904. NATIONAL LIFESPAN RESPITE RESOURCE CEN-**  
4                   **TER.**

5           “(a) ESTABLISHMENT.—From funds appropriated  
6 under subsection (c), the Secretary shall award a grant  
7 or cooperative agreement to a public or private nonprofit  
8 entity to establish a National Resource Center on Lifespan  
9 Respite Care (referred to in this section as the ‘center’).

10          “(b) PURPOSES OF THE CENTER.—The center  
11 shall—

12           “(1) maintain a national database on lifespan  
13 respite care;

14           “(2) provide training and technical assistance  
15 to State, community, and nonprofit respite care pro-  
16 grams; and

17           “(3) provide information, referral, and edu-  
18 cational programs to the public on lifespan respite  
19 care.

20          “(c) AUTHORIZATION OF APPROPRIATIONS.—There  
21 are authorized to be appropriated to carry out this section  
22 \$500,000 for each of fiscal years 2004 through 2008.”.

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108TH CONGRESS  
1ST SESSION

**S. 538**

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**A BILL**

To amend the Public Health Service Act to establish a program to assist family caregivers in accessing affordable and high-quality respite care, and for other purposes.

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APRIL 10, 2003

Reported without amendment